



REPORT from

# CLOSER LOOK

A Project of the Parents' Campaign for  
Handicapped Children and Youth

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## Budget Debate Begins

As we go to press, Congress is in the opening stages of a debate on the Administration's recommended budget for Fiscal Year '83 (beginning October 1, 1982), a debate which will have an important impact on federal assistance for special education. Current level of funding for federal grants to the states for education of the handicapped is set at \$931 million. The Administration's newly proposed budget asks Congress to consolidate these state grants with pre-school incentive grants (both currently under Public Law 94-142) and grants for state-run facilities for handicapped children. Funding for this proposed new special education block grant is recommended by the Administration at \$771.7 million. National organizations (such as the Association for Retarded Citizens, the Council for Exceptional Children, the United Cerebral Palsy Association, the National Society for Children and Adults with Autism, the Easter Seal Society, the Mental Health Association) are keeping up to date with information about Congressional action on the proposed budget. Their publications can help keep you informed; for additional information, get in touch with the office of your Congressional representative.

## A Man with Something to Say . . .

By any standards, Earl Brawner is a success story. A braille production assistant at the National Library Service for the Blind and Physically Handicapped, he has been with the Library of Congress for 16 years, reviewing brailled material for quality control. In 1978, Mr. Brawner was named Outstanding Handicapped Federal Employee of the Year.

At age 12, Mr. Brawner lost his sight and hearing. He attended both special schools and public school in the Washington, D.C. area, and went on to Gallaudet College for additional coursework. He is a man with something to say to parents and to others associated with people who have severe disabilities. He is fiercely independent, personable, and bright. He has succeeded against all the odds, and yet he feels he's not extraordinary. He shared his experiences and his philosophy with Closer Look in a recent interview. These are some of the highlights from that conversation.

*Q. Earl, what were your childhood and teen years like? Did you face much discrimination?*

*A. I would not say it was much, but it was around. I got some in my own family because they would not believe I was*

*(continued on page 6)*

## Communities are Classrooms For Children and Youth With Severe Handicaps

Until recently, institutionalization was the inevitable choice available to children with severe and profound handicaps. Parents were advised to seek placement out of their homes as soon as possible. And little or nothing (or nothing of value) was taught to these children. They were considered hopeless.

It would be too much to say that this attitude has disappeared entirely. But a tide of thought and feeling has turned—and with it, new ideas and practices have come about. Over the past ten years there has been a rise in recognition of the potential of children who were once perceived as society's "rejects." There has been an appreciation of their right to a high quality of life. More and more parents have insisted that their profoundly disabled children grow up with their brothers and sisters, in their own homes, going to school in their own neighborhoods, participating in the ordinary, everyday life of their communities. Forward looking educators have made strides in teaching appropriate behavior and skills that lead to work and independence.

## New Ideas Must Be Shared

There is, to be sure, a long way to go before these ideals are fully accepted and integrated into our culture. We need far more information about what works, as well as dissemination of what we already know.

It is encouraging that there are educators dedicating their intelligence and imagination to developing programs that work, that help to bring the most severely disabled children into the world we all live in. State and federal laws have mandated appropriate services for every child, no matter how profoundly handicapped. Organizations such as the National Society for Children and Adults with Autism and The Association for the Severely Handicapped bring together parents and educators who are working to translate these mandates into realities.

## Pointers For Effective Programs

One of the educators, Dr. Sharon Freagon of Northern Illinois University-DeKalb, recently pointed to specific factors that are essential to bring about effective community-based programs for children with severe disabilities:

- Parents must know how their children are being prepared for life after school. They need to ask—and get

*(continued on page 4)*

## Conference Keynotes . . .

### "Parent Power in the 80's: Collaboration"

The importance of cooperative action on behalf of handicapped children was the focus of the first national conference of the National Network of Parent Centers, held February 15-17 in Washington, D.C. The conference was coordinated by the Parent Center operated by The Federation for Children with Special Needs in Massachusetts, under the leadership of Martha Ziegler.

The theme of the conference, which was attended by representatives of 15 Parent Centers from all over the country, was "Parent Power in the 80's: Collaboration." Speaking at lunch on February 16, Jean S. Tufts, Assistant Secretary for Special Education, Office of Special Education and Rehabilitative Services, underscored the theme, pointing to the necessity for a sharing of responsibilities for services among community agencies. Mrs. Tufts encouraged parents to work for alliances among groups and organizations on local and state levels in order to foster cooperation in meeting needs of handicapped children.

### Comments urged on proposed new P.L. 94-142 regulations

In his keynote address, Dr. Ed Sontag, Director, Special Education Programs, presented an overview of Administration proposals related to education for handicapped children. Reporting on the status of review of regulations for Public Law 94-142, Dr. Sontag stated that an extremely high number of comments have been received and given thoughtful consideration, and that the draft of proposed regulations is nearing completion. The Notice of Proposed Rulemaking, containing proposed changes, is expected to appear in the Federal Register in April or early May, with a 60-day period for public comment. Both Mrs. Tufts and Dr. Sontag urged leaders at the conference to encourage parents to submit comments on the proposed regulations, when published.

### Participants share knowledge

Participants exchanged experiences and ideas at small group sessions on activities and operations of parent centers. Discussion centered on such issues as minority recruitment and training (led by Charlotte Des Jardins and Dan Fogel of Illinois); role of volunteers (led by Winifred Anderson of Virginia); meeting needs of individual parents (led by Marge Goldberg and Paula Goldberg of Minnesota); training materials and methods (led by Sally Hamburg of Indiana); funding (led by Jean Turner of California, and Martha Ziegler).

The program also included presentations on two innovative projects—one stimulating collaboration between parents and medical professionals, the other dealing with parent-media collaboration. "Networking with Washington-based resources" was the topic of a final session, addressed by a panel of leaders of the Parents' Campaign for Handicapped Children and Youth, Association for Retarded Citizens, Children's Defense Fund, American Coalition of Citizens with Disabilities and the Council for Exceptional Children.

### Conference results to be shared

This conference was a product of one of the Massachusetts Federation's federal grants designed to train parents to

utilize existing community resources. Virtually all of the parent centers invited to the conference began as grassroots coalition efforts and gradually developed more formal organizational structures. E. Catlin Donnelly, Assistant Director of the Federation, stated that the Federation will share results of the conference with other parent centers through its publication, *Coalition Quarterly*. She also recommended that newly formed centers request copies of *Coalition Quarterly*, a publication which focuses on issues unique to the development and operation of parent centers.

To follow up on the conference for materials or information, contact the Federation for Children with Special Needs, 312 Stuart Street, 2nd Floor, Boston, Massachusetts 02116.

## National Parent Network Fosters Sharing Of Information

The Parent Network, a new national coalition of parents of disabled children, will host its first official conference at the Red Lion Inn of Omaha, Nebraska, March 26-28. Author Robert Perske will be featured as keynote speaker.

Heading the Parent Network is Pat Koerber of Indianapolis, Indiana. Mrs. Koerber has been active in the parent movement through the Parent Information Resource Council (PIRC Inc.) in Indianapolis. The people who founded the Parent Network believe that a national, cross-disability coalition has important tasks to accomplish which can supplement the work of local coalitions and of groups related to specific disabilities.

### The goal: to build linkages and support

Some of the goals the group is weighing include linking parents whose children have rare disabilities and putting people in touch with current research. Its leaders hope to provide a linkage between parent groups and to facilitate the sharing of current information which crosses geographic boundaries and diagnostic labels. Specific information about local programs and services could be available through Parent Network linkages. In areas where chapters of other organizations are not available the Parent Network could be a source of parent support. Discussion of these and other possible goals will be a feature of the Omaha conference agenda.

In the brief time the Parent Network has been organized, it has recruited an all-parent board of directors drawn from all parts of the nation, and has organized the upcoming Omaha conference, to which it hopes to draw over two hundred parents. The group also plans to distribute the first issue of their newsletter, "Crisscross," edited by Martha Meyer of Indianapolis.

Speaking of the organizing process, Mrs. Koerber said, "It's moved slowly, but I'm very happy with what has happened. We've tapped different groups and different perspectives. Having a parent network will allow much more contact between groups and individuals."

### Where to write

For more information, write to: Parent Network, 1301 East 38th Street, Indianapolis, Indiana 46205.

Conference information is available from Amy Humphries, C. Louis Meyer Children's Rehabilitation Institute, 444 South 44th Street, Omaha, Nebraska 68105.

# Independent Living Skills Can Be Taught

Ten months after graduating from high school, Chris Falbo moved into Chapel Haven, a community which would help him learn independent living skills. He is a tall, handsome young man with dark brown hair and warm hazel eyes. He doesn't look disabled. However, he is learning disabled, and because of this, he has difficulty learning the ordinary tasks of daily life. He is making progress, but a lot of time, effort and systematic teaching have gone into his progress.

Chapel Haven is an unusual offshoot of the group home movement, one of the few residential programs in the United States that primarily serve learning disabled people. For a number of years, group homes have provided a place to live for young people with many different disabilities. They have used carefully structured approaches to help disabled individuals begin their adult lives and practice the skills they need to become independent.

## Learning self-help, step by step

The value of this concept is uniquely demonstrated in the programs for learning disabled people. They teach residents activities of daily living, such as cooking, budgeting, cleaning and shopping. The young people live in furnished apartments with roommates who are learning the same skills. Staff members live in the same building and provide step by step training and twenty-four hour supervision; public transportation is available for travel to work and recreational opportunities.

We recently contacted four programs:

- Chapel Haven, New Haven, Connecticut
- Jewish Special Young Adults (JESPE) House, Orange, New Jersey
- Success Through Independent Living Experience (STILE), Asbury Park, New Jersey
- Terry's Residence for Young Adults (TRYA) Hostel, Hempstead, New York

## Practice and coaching improve social skills

For many learning disabled young people, the most difficult problem is learning acceptable social behavior. Because of their disability, they frequently do not pick up social cues; this can create problems in fitting into social groups and developing appropriate friendships. However, these social skills can be taught in the same structured way that academics and daily living skills are taught. The staffs of these residences use many approaches to teach conversation, self-control and constructive ways of dealing with conflict.

Socialization groups are used as a means of teaching acceptable ways of entering and leaving conversations and making small talk in social gatherings. Role-playing is used to practice asking a friend out for a movie or discussing the latest football game. Organized social activities encourage residents to use community and cultural resources successfully.

Learning how to handle social situations can be tremendously encouraging to young people who have been rejected because of social awkwardness. One young woman said:

"Here, I've learned how to get along with people, how to make friends. Before I came here, I can't say I had true friends. The director helped me. I had a session with him by myself and we talked about how to start a conversation and how to talk to a person. We rehearsed conversations."

## Families are eased through transition

For most families, the process of separation and beginning independence is hard; the transition can be rocky for parents and children alike. The directors of these residences feel that supporting families through the transition is an important challenge. As one explained, "To help with the letting go process, we educate the parents about their child's real abilities. It takes time and support and commitment. It takes time to adjust."

## Jobs are key to independence

The most important challenge in being able to live independently is to find a job that will enable a young person to be self-supporting. For a person with a learning disability, a part of that challenge is to make a choice that is appropriate to his or her own strengths. A person who has trouble understanding money concepts should not seek a job as a cashier, for example. Preparing for a job must include the following steps for success:

- Careful evaluation and assessment, geared to develop a full profile of abilities as well as difficulties;
- Training that is in accord with the information developed in evaluation—as well as taking the local job market into account;
- If possible, trying a variety of activities and skills; pre-vocational and work-study programs can be very effective in suggesting new possibilities;
- Teaching job-related behavior—promptness, reliability, appropriate dress;
- Finding a job appropriate to each person's skills and potential;
- Follow-up by a counselor to make work adjustment go smoothly by helping to solve any problems that arise.

When this process works well, it can be the most liberating event in a young person's life. One young woman who was encouraged and assisted to become a nurse's aide was overjoyed:

"When they (Vocational Rehabilitation) suggested that, she lit up like a Christmas tree. She was really excited, because her older sister is a nurse, and she had never thought she could do a job like her older sister."

She is now working, loving her work, and taking classes to increase her skills.

Learning disabled young people, like the rest of the world, find that working every day loses its novelty. Going to work when it's snowing—or perhaps when your friends are headed for the beach—can be hard for anyone. Counselors help the residents through these adjustments and encourage them to take pride in their work and their paychecks.

*(continued on page 4)*



These pioneering programs for learning disabled young adults have helped many graduate into independence and a place of their own. Each program grew out of parents' and professionals' concern for young men and women who graduated from high school with no direction in their lives. The ideas they have used, the techniques they have developed and the innovative use of community resources can be adopted by parent and community groups in other areas. Young people can take those first steps away from home and learn at their own pace to develop their full potential as independent adults. It takes time, planning, persistence, money, and development of community awareness and support to put together a successful program—but the benefits in human and economic terms are enormous.

### Parents can establish needs, design response

How can parents and interested professionals work within their communities to encourage such programs? The first step is to survey their own community: What is happening to young people when they graduate? What is available in the community in terms of vocational training, social services and continuing education geared to the needs of learning disabled people? Are there any ways to reach community leaders who may be able to contribute help of different kinds?

Once the dimensions of the need are established, groups can begin to set goals, establish priorities and determine the best way to design a program that is effective for their own community. The training component of a program may be all that a given community can or will support; other communities may have larger populations or other special circumstances that make a residential program feasible. The important point is to meet the needs of young people who need extra help in achieving independence. Their pride in achieving these successes is expressed by one young man who said:

"What would I have done at home? Just sit around? Watch TV and listen to music? Now I have learned to cook, learned to clean and learned to budget. I have a job."

Modest achievements? Perhaps; but ordinary daily life is made up of such modest achievements. Well-designed programs for independent living can help young people with all kinds of disabilities to lead the fulfilling, independent lives we want for all our children.

— Dale Brown of the President's Committee on Employment of the Handicapped and Marie Ormsby

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## For Public Officials . . .

**Beyond Paternalism: Local Governments and Rights of The Disabled** is based on actual experiences of seven local governments that have done significant work toward promoting equal rights of disabled citizens. The book is filled with excellent, down-to-earth and cost-effective suggestions for removing barriers—including the attitude barrier.

Organizations and individuals will find this book a means of capturing the interest and commitment of their public officials. For a copy, write to the International City Management Association, 1140 Connecticut Avenue, N.W., Washington, D.C. 20036. Cost: \$15 plus \$2.25 processing charge.

answers to—such questions as: Is my child learning as much as he can about appropriate social behavior? Is the school program helping him develop independence, take care of personal needs, use public transportation, cross streets safely, learn work skills?

- Teachers and other professionals must work closely with parents as colleagues in developing individual goals for each child. In addition, educators should be afforded the time, opportunity and support to have inservice training and to keep up with the state of the art in teaching severely handicapped young people.

- School board members must be reached and oriented to the goals of special programs, so that these innovative efforts receive support. Parent groups, as well as school staff and administration members, can take the lead in reaching school boards, making sure that effective programs are highly visible, and that their purposes and results are understood. With information in hand, board members can advocate within the community at large about the need to serve severely handicapped students in appropriate programs, interacting with the real life of school and community.

- Community leaders should be involved. It is important to make presentations to civic and business groups about programs geared to integration of people with severe handicaps. Other activities can help, too—films, field trips to quality programs, TV and press coverage. Most effective of all is the impact of the everyday presence of severely disabled children, youth and adults who are being educated to live and work in the community.

- School and community resources must be coordinated so that a smooth transition takes place *after* high school. This means that community resource people, from leaders of day activity centers to employers, must work with educators to ensure that students not only maintain the skills they have, but continue to learn and develop new skills.

These points were made by Dr. Freagon in an address to parents of severely handicapped children who attended a recent invitational conference in Washington, D.C. The meeting was sponsored by the Department of Education, Special Education Programs. Dr. Freagon described the philosophy, design and implementation of a program for severely handicapped students in DeKalb County, Illinois, in which a team of educators from Northern Illinois University-DeKalb and the DeKalb County Special Education Association teach the students skills they need in order to participate in community life.

### "Give them power"

The central goal is to "give them power in every one of their environments." Creative ideas and teaching aids are used to instruct the students in using the natural environments which are part of everyday life—apartments, stores, banks, recreation facilities, fast-food restaurants.

There are no "field trips," in the sense of bringing a group of students to a business that was prepared for their arrival in advance. Instead, teachers go with one, two or three students on a day-to-day basis to practice in the community the skills they rehearse ahead of time: selecting food items, using vending machines, crossing streets safely and independently—all activities that non-disabled people take for granted.

As Dr. Freagon described it, a sound learning program for severely handicapped students must:

- be functional for each child, moving from one truly needed skill to the next—from putting on a jacket to mastering the zipper, for example.
- be appropriate for the child's *chronological age*—teaching a fourteen-year-old to use a soft drink machine, instead of teaching him to wash his hands for the fourth year in a row.
- provide skill training in a student's present and future natural environment, so that with their families and friends, or by themselves, they can use what they learn during school hours to go out into the community to buy a hamburger or make a bank deposit.
- be longitudinal; that is it must prepare each student to move on with functional, age-appropriate skills, just as first grade prepares a child to move on to second grade.
- be able to make adaptations that will help an individual child become more independent, such as teaching a non-verbal youngster to use a communication board or a picture shopping list at a grocery store.
- provide for transition to the next setting, so that each student has seen and participated in the school, or workshop, or workplace and has learned skills needed to participate before the actual move is made.
- assess each student's progress, based on his or her own learning program and on actual performance in the community or environment where each will be in the immediate future.

### Teach skills children really need

Education for severely and profoundly handicapped children, then, must have the same purpose as any other education: it should teach skills needed to function in the community. The key is functionality, and goals should always be chosen with that in mind. A statement by Dr. Lou Brown, Professor of Behavioral Disabilities at the University of Wisconsin in Madison sums it up:

"We have a general rule that we try to follow. We ask ourselves this, 'If the student doesn't do it, does somebody else have to do it?' Observe a classroom. If the student has a plastic ring and a plastic cone, and if he doesn't stack them, is somebody else going to have to do it? If not, then you can't call it a functional skill. Think about all the things that we ask our students to do—sort plastic money and package pink fuzz. It doesn't matter whether or not the children do these things, because nobody else is going to." (Quoted from the *Journal of Special Education Technology*, Volume IV, Number 2, Spring 1981)

### Madison practices community participation

Dr. Brown's comments, quoted above, describe the philosophy behind an integrated program that the Madison, Wisconsin public schools have developed since adopting a "zero reject" policy in the early 1970's. Beginning at birth, families may receive services to assist a child with a handicap or developmental problem. The school system places everyone in age-appropriate schools, including secondary schools. This gives the most severely disabled students the chance to observe and learn from ordinary behavior

patterns, while their non-disabled peers learn understanding and tolerance of differences.

This belief that severely handicapped students should not be separated from their peers extends into the community in Madison. As Dr. Brown pointed out, "If you want to teach a student to perform in a particular environment, you have to go to that environment and teach him." Madison has seven teachers who work with the community, teaching skills, knocking on doors to find new work placements for students and helping them increase their ability to work independently. What are some of the kinds of work they are doing?

- Hotel restaurant and laundry work
- Hospital cleanup
- Unpacking boxes in stores
- Assisting in nursing homes
- Stuffing envelopes for businesses
- Recycling used machine parts

### Let's disseminate successful ideas—and use them!

At present, there are about three hundred students from infancy through age 21 who are served by the Madison school district. There are thousands of young people all over the nation who could benefit from what has been learned in Madison, in DeKalb and in other exciting programs. Parents can use these ideas to recognize and encourage functional programs. Efforts of this type can help to answer the tough questions: What happens after high school? Will the end of school signal the beginning of aimlessness and waste—or will there be hope for usefulness, participation, joy?

These are questions that have significance for everyone—not only parents and teachers, but businessmen and public officials. The costs of waste, of institutionalization and neglect, are incredibly high. There is an urgent need for widespread dissemination about the effectiveness of programs now being carried on by parents and professionals who believe in a meaningful future for *every* child, no matter how disabled.

— Marie Ormsby

able to do anything. In other cases it was because they just didn't want to be with a handicapped person. But, of course, it *hurt*. And I fought against it. Helen Keller and others before her underwent the same experiences. They met with fear and avoidance.

*Q. I read in your background material that you became disabled at age 12. What was your education like?*

A. First I went to Perkins, but my speech was too good for their program. Afterwards I went to Overlea School for the Blind. Then I came back to Washington, D.C. and for two years I went to public school at Roosevelt High and graduated from there—which goes to prove that a deaf-blind person with a companion can go to public high school. In algebra I was called “The Master.” I believe that other deaf-blind persons could do the same thing. They could even go all the way through elementary school, senior high, and college (of course with companions) quite effectively. I believe that the deaf-blind can successfully go to school and learn and benefit from it. But they have to have pride in themselves to want to learn.

*Q. You are a member of two minority groups—you have a disability and you are black. Do you think that blacks with disabilities have different problems?*

A. They have more problems with discrimination.

*Q. From your experience, how can disabled blacks overcome this problem?*

A. There is only one way in which I know, and this is to excel to the fullest in employment and education. Be the best in employment and do your best. Take a job that gets you out among people, such as mine.

## Let children learn independence

*Q. Do you have any advice for parents of deaf-blind children?*

A. Yes, I have some advice for parents, because I have undergone some problems as a result of this. And I discovered it could be harmful if a father and a mother, other adults, even other children in the family or neighborhood, try to force a deaf-blind child *not* to do something that would influence his independence and self-reliance later. At first, when a child becomes deaf-blind, it is necessary for him to feel things and to feel people's faces in order to see them by touch. So many parents and other people do not want him to touch people and I'm sure you know why.

*Q. Why?*

A. Because many people think that being touched or being too close to a handicapped person causes a so-called “normal” person to become likewise handicapped. Of course, it's stupid. It's still in sway, though. It is necessary for parents and others to come in close contact with deaf-blind children to understand, and love, and treat them the same way they would treat a so-called “normal” kid. With one exception . . . do not take advantage of the child's handicap in order to get the parent's will done.

*Q. That's very good advice.*

A. The parent has to treat the deaf-blind child the same. Take him out in the neighborhood, introduce him to people, shake his hand. Take him to stores and other places so that he can be used to doing it. And then, in his teens, it will not frighten him to do this alone in public. He must get confidence that he can operate alone. That's what I did and I go out alone. I get my own taxi cabs, go into stores and order what I want, go to supermarkets and get what I have to with

the assistance of somebody there or even from the clerk. I go to barber shops, go to restaurants . . .

*Q. So the important thing is for parents to allow their children to be independent? And to teach them the skills they need to be independent?*

A. Yes, independent and self-reliant. And if they have intelligible speech, have them use it. If not, teach them to be sociable. But in order to be sociable, the child has to be loved and made to feel he is worth something.

## Self-reliance, participation are important

*Q. What do you have to say to young people who are deaf-blind?*

A. Only one piece of advice—that they, themselves, are causing their own fear. They are quite capable of leading a better life than some so-called “normal” people. That's a fact. I have seen it.

*Q. It's been a real pleasure to meet you and to talk with you. You've said a lot of things that will be helpful to the readers.*

A. And I thank you for having made it possible for me. I am happy to have had the pleasure of being able to speak a little bit to try and help. I really am.

Mr. Brawner communicates through the use of American Sign Language and the manual alphabet. He can also read letters traced with a finger on the palm of his hand. He believes strongly that deaf-blind individuals have a right to be heard and to participate in the mainstream of life. To this end, he is aiding in the development of a communication device, the Deblicom Code, which allows deaf-blind persons to use a telephone-braillewriter machine. Mr. Brawner is an active spokesperson for the civil rights of severely handicapped citizens. We thank him for contributing his thoughts.

— Debra Cornelius

## For Teenagers

Independence can be fostered in many ways. A new booklet, produced by Closer Look, provides a self-help tool for teenagers with physical disabilities in their quest for independence. The publication, **Taking Charge Of Your Life: A Guide To Independence For Teens With Physical Disabilities**, is a collaboration between Closer Look and the Center for Independent Living in Berkeley, California and was written by successful adults who have themselves been disabled teens. The booklet draws on their personal experience, shares their solutions to problems and reflects the doubts and concerns that they had to overcome on their way to independence.

Individual chapters of the booklet focus on family life, social life, school and planning for the future. Participation in family, school and community life is encouraged, with practical ideas and suggestions on how this can be achieved.

A single copy of this publication may be obtained by writing to: Parents' Campaign For Handicapped Children and Youth, 1201 16th Street N.W., Washington, D.C. 20036.

**Taking Charge Of Your Life** is also available for teens who are eligible for the Library of Congress program of recorded material; it has been taped on cassette by the District of Columbia Regional Library for the Blind and Physically Handicapped in Washington, D.C. Your nearest public library can put you in touch with the network of regional and subregional libraries which serve blind and physically disabled people.

## Books for Children That Tell Good Stories—and Teach, Too!

**B**ooks are a great way for children to become acquainted with new people and new ideas. A child absorbed in a book is living it, and sees the world through different eyes. This is why we want to share some good new books for children, books about other children who have disabilities. We think this list is full of good stories that touch on the happiness and sorrow of ordinary life—and if they also teach a child to understand disabilities and how people learn to live with them, that's a bonus. We hope you will encourage your school and public libraries to add these new books to their collections.

*A Signer's Story* by L. B. Kingman, Houghton Mifflin Company, 2 Park Street, Boston, Massachusetts 02107 (1978) 186 pp.

Done in cartoon style, this is an amusing, effective illustration of what signing is, how deaf and hearing people use it to communicate, and how much most people already use their hands to express themselves. Includes the manual alphabet, signs for many common words, and a story about a boy who learns signing from a new friend who is deaf.

*Angie And Me* by Robert C. Fuchs, Macmillan Publishing Co., Inc., 866 Third Avenue, New York, New York 10022 (1981) 113 pp.

The experience of being hospitalized is seen through the eyes of twelve-year-old Jenna, whose life is disrupted when she develops juvenile rheumatoid arthritis and goes into a hospital for treatment. She learns to cope with being away from home, with the pain and uncertain outcome of her own illness, and with loss, through the death of one of her hospital friends.

*Alesia* by Elise Greenfield and Alesia Reris, Philomel Books, division of The Putnam Publishing Group, 200 Madison Avenue, New York, New York 10016 (1981) 61 pp.

This true story, illustrated with photos and drawings, is the diary of a high school senior who was struck and nearly killed by a car when she was nine. It portrays her life at home, at school and at work and her determination to be able to walk across the stage at her high school graduation on her own.

*Ride The Red Cycle* by Harriette Gillem Robinet, Houghton Mifflin Company, 2 Park Street, Boston, Massachusetts 02107 (1980) 34 pp.

A determined, proud young boy teaches himself to work around his physical disability and surprises his family—and the whole neighborhood—by proving that he *can* ride his beautiful red tricycle.

*Through Grandpa's Eyes* by Patricia MacLachlan, Harper and Row, Publishers, Inc., 10 East 53rd Street, New York, New York 10022 (1979).

A young boy learns through his companionship with his blind grandfather how rich his life is in the sounds, tastes, aromas and feelings that are also part of the sensory world.

*Sports For The Handicapped* by Anne Allen, Walker Publishing Company, Inc., New York, New York (1981) 80 pp.

Real people with disabilities who have become winners in a variety of adapted sports are featured in this interesting,

generously illustrated book. The point is made throughout that sports are for everyone, not just for those who are champions. Adapted skiing, wheelchair basketball, swimming, horseback riding and other sports are all illustrated, and a list of recreational organizations for disabled children and adults is included.

*Head Over Wheels* by Lee Kingman, Houghton Mifflin Company, 2 Park Street, Boston, Massachusetts 02107 (1978) 186 pp.

This is a story of teenage twin brothers and how they learn to cope with the aftermath of an accident that leaves one of them quadriplegic. It takes an honest look at the toll taken by severe accidents—the physical and emotional pain, the financial burden and the gradual realization that there is no going back to the way life was before.

*The Seeing Summer* by Jeannette Eyerly, J.B. Lippincott, New York, New York (1981) 153 pp.

Carey's new neighbor turns out to be a ten-year-old girl, just as she is—but Jenny, the new girl, is blind. It is Carey's first experience with a blind person, and at first she has trouble adjusting to the idea that Jenny is capable and independent. Their adventures in becoming good friends make interesting reading.

*The Alfred Summer* by Jan Slepian, Macmillan Publishing Co., Inc., 866 Third Avenue, New York, New York 10022 (1980) 119 pp.

This award-winning book is the first of two that tell about the relationship between two young boys—Lester, whose movements and speech are affected by cerebral palsy, and Alfred, who is retarded and physically handicapped. Their friendship is detailed in a touching, human way.

*Lester's Turn* by Jan Slepian, Macmillan Publishing Co., Inc., 866 Third Avenue, New York, New York 10022 (1981) 139 pp.

In this second book, Alfred has been placed in a hospital because of his mother's death and his own physical deterioration. Lester's scheme to take him out of the hospital and care for him ends when Alfred dies; Lester is forced to look at his own life and move on toward independence and maturity.

**REPORT From Closer Look** is a publication of The Parents' Campaign for Handicapped Children and Youth

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# A Word About the Parents' Campaign

**P**arents have no special preparation for raising a child with a handicap. And yet, the fact of a disability in their child's life brings with it a vast number of challenges and choices that must be met, often on a daily basis. Almost all of the challenges are new ones for all of us; there are times when they are overwhelming.

The Parents' Campaign for Handicapped Children and Youth was formed to provide practical assistance to families facing these new and often difficult demands. The organization's founders were parents who had been through the mill and understood the importance of a national center to which parents of handicapped children and youth could turn. We believed (and still do) that parents are the leading experts on their child's needs, and have the principal responsibility for their child's development. They must be involved, every step of the way, in working with professionals on education and health plans that affect their child's future.

We know from experience that parents must teach themselves to understand their child's disability, and then go on to teach others—their own families, and people who work with their child in school and in the community. They must repeatedly remind others that their child, no matter how severely disabled, is a person first, with valued strengths and individual potential to respect and nourish.

The program of the Parents' Campaign is designed to help families of disabled children deal with the complex set of needs they face: locating services, communicating with professionals, asserting and interpreting individual needs, working with different community agencies, knowing their rights and how to implement them, organizing with other parents to help bring about change. The organization's goal is to help to create a positive environment, one which encourages each handicapped individual to achieve the greatest possible fulfillment and independence.

The activities of the Parents' Campaign relate to *all* handicapping conditions, including those most profoundly disabling. We work with all other organizations concerned about disabilities, on national, state and local levels—not supplanting their roles, but integrating our efforts with theirs. The services we provide span needs that arise from birth through adulthood.

## Parents' Campaign for Handicapped Children and Youth

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Our purposes have been furthered by our major projects:

- **The Closer Look Information Center**—which has responded to more than 30,000 requests for help each year since its beginning, 12 years ago. Requests have come from parents, disabled adults, professionals in special education, health and other fields related to disabilities, organizations, students and other concerned individuals. Closer Look has developed a wealth of information to respond to wide-ranging inquiries, from questions about diagnosis to requests for information about preparing for independent adult life.

- **Project Bridge**, a unique training project designed to improve the capacity of parents and professionals to communicate with one another as equals, respecting one another's point of view and laying the groundwork for ongoing partnership for handicapped children.

The project, still in its early stages, will eventually produce a model training curriculum for widespread use by parent and professional groups. The project is jointly sponsored by the Parents' Campaign and The Council for Exceptional Children.

- **The HEATH/Closer Look Resource Center**, a national center which disseminates information about post-secondary opportunities for disabled men and women. This project is a combined effort of The American Council on Education and the Parents' Campaign.

- **Obstacles to Parent Involvement**, a significant research project focusing on barriers to school participation faced by black parents living in inner city areas, whose children require special education. Results of this project should yield valuable information which will increase knowledge and use of inner city resources and support networks for black parents of handicapped children and youth, encouraging understanding and interaction between parents and schools.

Please write to us to find out more about our activities, publications and plans. We want to hear from you!

— Barbara Scheiber

